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The Nutritional and Social Contexts of Celiac Disease in Women: A Qualitative Study

Julián RODRÍGUEZ-ALMAGRO[1]* • David RODRÍGUEZ-ALMAGRO[2] • MCarmen SOLANO-RUIZ[3]
José SILES-GONZÁLEZ[3] • Antonio HERNÁNDEZ-MARTINEZ[4]

ABSTRACT

Background: Previous studies have confirmed that women who are diagnosed with celiac disease report a lower quality of life than men who are diagnosed with the same illness.

Purpose: This article describes the life experiences of women with celiac disease, especially those who adhere to a lifelong gluten-free diet.

Methods: A phenomenological design based on the Giorgi method was used. Twenty-two women who were diagnosed with celiac disease and were between 16 and 75 years old completed the semistructured interviews.

Results: The results showed that celiac disease has differing effects on the lives of women sufferers. The general feeling of being a woman with celiac disease was described as an effort toward achieving a normalized life. Four categories emerged from the results: feelings at diagnosis, limitations in daily life, social perceptions of the illness, and personal meanings of celiac disease.

Conclusions/Implications for Practice: This study shows that celiac disease and its treatment reduce mental and social quality of life in women. Organizations and public institutions should carry out public awareness campaigns targeting celiac disease and promote quality of life in sufferers of celiac disease in general.

KEY WORDS:
chronic disease, celiac disease, illness experience, phenomenology research, qualitative research.

Introduction

Celiac disease (CD) is a common chronic illness that is caused by an inflammatory response to gluten proteins. Gluten causes atrophy of the villi in the small intestine of patients with CD, which may lead to the malabsorption of nutrients (Elli et al., 2015).

Although the prevalence of CD is 1% globally, there are large variations between countries (Lebwohl, Ludvigsson, & Green, 2015). This was confirmed in a recent multicenter study in Europe, which showed a prevalence that varies between 2% in Finland and 0.3% in Germany (Mustalahti et al., 2010) as well as percentages of 1%–2% in the adult population of Western Europe (West et al., 2003). Recent studies have shown that, in North America and Europe, the number of new cases of CD found in a determined period in a given population is rising (West, Fleming, Tata, Card, & Crooks, 2014).

All epidemiological studies have repeatedly documented a global predominance of CD in women, with a female-to-male ratio of 2.5:1–3:1 (Zingone, West, et al., 2015).

The only treatment for CD is a strict, lifelong gluten-free diet (GFD; Pulido et al., 2013). No foods or medicines containing wheat, rye, or barley gluten or their derivatives may be consumed, as even small amounts of gluten may be harmful.

Although conceptually simple, these changes in diet are substantial and have a profound effect on a patient's life. Untreated CD is associated with complications, including an increased risk of mortality, most of which may be avoided by following a strict GFD. However, there are many barriers, including the availability, cost, and safety of gluten-free foods, and gluten cross-contamination. The GFD may be restrictive in social situations, leading to poor quality of life and, ultimately, nonadherence (Kaukinen, Makharia, Gibson, & Murray, 2015).

As the number of patients with CD increases worldwide, clinicians need to be aware of the challenges that patients face. Heightened awareness among physicians, dietitians, and other providers is critical to maximizing successful treatment, improving outcomes, and reducing healthcare costs and disease burden. Routine follow-up is necessary to reinforce the need for a GFD, provide social and emotional support, and achieve mucosal healing, leading to a reduced risk of complications. Unfortunately, there is a wide variation in follow-up practices (See, Kaukinen, Makharia, Gibson, & Murray, 2015).

When an individual is diagnosed with CD, he or she must face important life changes. The perception of being afflicted with a chronic illness and the need to follow a restrictive,

[1]*PhD, RN, Nurse, Department of Emergency, University General Hospital of Ciudad Real, Ciudad Real, Spain* • [2]*MSc, RN, Nurse, Department of Emergency, University General Hospital of Ciudad Real, Ciudad Real, Spain* • [3]*PhD, RN, Professor, Department of Nursing, School of Health Sciences, University of Alicante, Alicante, Spain* • [4]*PhD, RN, Nurse Midwife, Nurse Midwife Teaching Unit, General Hospital Mancha-Centro, Alcázar de San Juan, Ciudad Real, Spain.*

demanding, and permanent diet, together with periodic medical checks and the possibility of finding out that other family members are affected, mean that the illness has a significant psychosocial impact (A. Lee & Newman, 2003).

As a general rule, after establishing a GFD, the patient with CD will experience a significant improvement in symptoms in a matter of days or weeks (Autodore, Verma, & Gupta, 2012). However, permanently changing dietary habits in an adult poses many problems (Touchy & Jett, 2016), and despite strictly following the diet, many adults never reach the same subjective level of health as the general population (Mulders-Jones, Mitchison, Girosi, & Hay, 2017).

Prior research (Jacobsson, Hallert, Milberg, & Friedrichsen, 2012) shows that the disadvantages related to having CD and following a GFD are more pronounced in women than in men. This suggests that the signs of general malaise should not be attributed to CD itself but rather to complications in adjusting to the nature of the illness (Roos, Kärner, & Hallert, 2009).

Previous studies confirm that women who are diagnosed with CD report a lower quality of life than men who are diagnosed with the same illness (Jacobsson et al., 2012) because of restrictions in day-to-day life (Hallert, Sandlund, & Broqvist, 2003) and in their social lives (Hallert et al., 2002). These previous findings suggest that there are gender-related indications that should be taken into account to understand the difference between men and women with CD.

Recent studies have shown gender differences (Sverker, Östlund, Hallert, & Hensing, 2009) by studying the day-to-day dilemmas of men and women with CD. Although the general patterns are similar, men and women report different social situations in relation to buying and preparing food (Mathew, Gucciardi, De Melo, & Barata, 2012).

Few studies have focused on describing the perceptions of CD in women, and it seems important to explore and uncover these experiences in greater detail to improve support for women in relation to this illness throughout their lives and to provide them with valid strategies for supporting their lifelong, strict GFD.

Therefore, the aim of this study was to describe the life experiences of women with CD, especially those who adhere to a lifelong GFD.

Methods

A study was carried out using a qualitative methodology and semistructured interviews with women with CD. A qualitative methodology is especially useful in understanding a phenomenon from the point of view of those affected by exploring their beliefs, expectations, and feelings and in explaining the reasons underlying their behaviors and attitudes.

Purposive sampling was conducted by (Guetterman, 2015) interviewing adult women with CD who had contacted the research team after having seen appeals that were made between January and April 2016 through celiac associations in Spain and in celiac groups on social networks.

The only criterion for inclusion was to be a female sufferer of CD between 16 and 75 years old. Duration since diagnosis, an important factor affecting adaptation to disease, was not considered in recruiting participants. Convenience sampling was used and was carried out until data saturation had been achieved (Leung, 2015).

Semistructured interviews were conducted. Sociodemographic data collected included age and time since diagnosis with CD. A semistructured script was followed, and interviews were transcribed in their entirety. All of the participants signed informed consent and took part voluntarily. The anonymity of participants and the confidentiality of the information provided were maintained throughout the study and in subsequent public presentations of results. Furthermore, all of the requirements established in the Helsinki Declaration were followed, thus guaranteeing against future ethical problems that could arise from the research.

The participants were identified by codes to safeguard their anonymity, and their statements were identified by the letter E (for "entrevista" [interview]) followed by a sequential number from 1 to 22.

All of the interviews began with an open question (Applebaum, 2012) that invited the participants to relate their experiences living with CD and to focus on the problem: "What is it like for you living with celiac disease?" The interviewees were encouraged to relate their experiences with the illness freely, and the interviewer followed the script freely to encourage the interviewees (Kim & Oh, 2016).

The interviews were analyzed manually based on the Giorgi method, an approach that aims to describe the meanings of a phenomenon from the perspective of the life experiences of a person (Giorgi, 1997) through essential topics. This method facilitated a description of the experiences of women living with CD by categorizing all of the findings into units of meaning based on the philosophy of Edmund Husserl and Merleau-Ponty, an approach that is sufficiently generic to be applied to any science (Applebaum, 2012).

The text of the interviews was therefore analyzed in the following manner (Giorgi, 1997; Jacobsson et al., 2012):

Transcription: The interviews were read while the tapes were listened to in order to obtain an initial superficial interpretation. This step offered ideas on the meaning of the whole and how to proceed with a deeper analysis.

Elaboration of units of general meaning: The interviews were read once again, but this time with the aim of identifying the smallest parts, the units of meaning, within the perspective of the phenomenon of being a woman living with CD.

To avoid theoretical explanations, the data were kept to the most specific level possible. One unit of meaning may be part of a sentence or a paragraph.

Elaboration of units of meaning relevant to the theme of the investigation: Taking as a reference the units of general meaning identified in the previous step, the researchers selected the units of meaning that related to the research theme. When the themes were repeated

in the units of meaning, the researchers sought convergences and divergences and categorized themes accordingly. The repetition of themes indicated that it was possible to obtain the essence or meaning of the phenomenon studied.

Verification of the relevant units of meaning: After the units of meaning relevant to the investigation had been identified, the researchers established criteria that grouped the units of meaning into categories reflecting common aspects or characteristics. These categories constituted a new element that allowed a set of relevant units of meaning to be named under one epigraph, theme, or issue.

The process of selection created unit groups, each reflecting a distinct meaning. From these groups, the themes, which show the meaning of experiencing or living a specific phenomenon, were identified and interpreted. The general structure, that is, a new group, was synthesized in a representation of the phenomenon of being a woman living with CD.

During the process, the criteria that were used to ensure methodological rigor in terms of credibility, auditability, and transferability were taken into account (Cornejo Cancino & Salas Guzmán, 2011).

Credibility refers to the level of confidence in the truth, value, or believability of a study's findings. Credibility is shown through strategies such as data and method triangulation (use of multiple sources of data and/or methods), repeated contact with participants, peer debriefing (sharing questions about the research process and/or findings with a peer who provides additional perspective on analysis and interpretation), and member checking (returning findings to participants to determine if the findings reflect their experiences; Polit & Hungler, 2000).

Auditability refers to the documentation, or paper trail, of the researcher's thinking, decisions, and methods related to the study. Field notes, memoranda, transcripts, and the researcher's reflexive journal or diary allow the reader to follow the researcher's decision making (Polit & Hungler, 2000).

The transferability of research findings refers to the degree to which the findings of a study fit beyond its specific context. Fittingness refers to whether the findings have meaning for another group or may be applied in another context. An accurate and rich description of research findings shows fittingness or transferability by providing adequate information to evaluate the data analysis (Polit & Hungler, 2000).

Ethical Considerations

The study design was reviewed and approved by the appropriate institutional ethics review board (no. 12/2013). Participants provided oral and written consent to participate.

Results

The median age of the participants was 31.68 years, and all were undergoing treatment with a GFD. The rigorous review of the interviews allowed the researchers to identify four categories representing the experience of being a woman with CD: feelings at diagnosis, limitations on day-to-day life, social perceptions of the illness, and personal meanings of CD.

Feelings at Diagnosis

Participants reported a lack of information at diagnosis. They expressed feelings of fear and anger toward the unknown, which represented their first true awareness of their illness. However, they concurrently expressed feelings of relief about knowing their condition and perceived that, with a lot of training, they would be able to coexist with their illness:

> *I felt a mixture of anger at what was happening to me and at the little information they gave me at the time, and that I couldn't lead a normal life because of food.* (E2)

> *When they first tell you, it really shocks you, and you don't know if that is what is really happening to you. He told us about the risks and told my mother that I could die, and that's not easy…a mother being told that her daughter could die. Thankfully that is difficult when you know the illness, and my mother and I have been calmer since then.* (E1)

Limitations in Daily Life

The interviews reflected participant experience; regularly following a GFD affects social life. Some were reluctant to go to parties or restaurants because they were unsure of the ingredients of dishes and were also concerned about the possible contamination of cutlery. Social life was perceived as less enjoyable when it revolved around eating with others outside the home, and participants largely viewed eating at home with others as less problematic.

> *Sometimes you even feel embarrassed to order something gluten-free. You just shut up and drink your Coca Cola.* (E7)

Social Perceptions of the Illness

Participants in this study and previous studies reported social situations involving negative emotions in relation to gluten-free food and a GFD (A. R. Lee, Ng, Diamond, Ciaccio, & Green, 2012).

> *It is an illness that isn't viewed the same as others, like diabetes.* (E14)

On a trip to Istanbul I ended up only eating salads for fear of eating something with gluten and doing myself harm. (E4)

Personal Meanings of Celiac Disease

Participants tended to manage their GFD better and thus show reduced anxiety and fear, over time, in this study as well as in previous studies (DiMatteo, Haskard-Zolnierek, & Martin, 2012). However, if levels of anxiety and fear do not decline with time, it may indicate that patients need more confidence in their diet control strategies (Black & Orfila, 2011; DiMatteo et al., 2012).

Society should be made aware about CD. (E11)

In restaurants, there is a lack of training and awareness, and they should consider separating foods, work areas, utensils, and so on. (E12)

Discussion

The results of this study indicate that CD manifests in many different ways in the life of women sufferers. Some of the participants reported that CD had very little effect on daily life, whereas others experienced the illness as a burden. However, all agreed on one issue, which was the normalization of their lives. This is consistent with other studies, which show that most chronically ill people exhibit the desire to achieve a semblance of normality in their lives (Jacobsson et al., 2012). Women with CD who have a stronger sense of security and control tend to have a greater sense of normalcy.

Previous research (Ludvigsson, Reutfors, Ösby, Ekbom, & Montgomery, 2007; Smith & Gerdes, 2012) provide data related to the association between GFDs and negative emotions, including anxiety and depression, which was found in this study. Psychosocial factors may have a stronger effect on health-related quality of life than the CD itself (Sainsbury, Mullan, & Sharpe, 2013). Patients, especially female patients, with CD have higher rates of anxiety and depression than the general population (Arigo, Anskis, & Smyth, 2012; Smith & Gerdes, 2012; Zingone, Swift, et al., 2015).

As in previous studies (See et al., 2015), this study showed that insufficient education about GFD increased the risks of poor adherence and frustration and increased healthcare costs because of patients seeking medical care for ongoing symptoms and/or complications.

Moreover, the participants expressed concern about the future in terms of both their professional and personal lives. This may indicate that many of the feelings expressed by the participants (loneliness, having no one to talk to, and the feeling that nobody cared) may be more prominent in women with CD than in their male counterparts (Roos, Hellström, Hallert, & Wilhelmsson, 2013).

Although the requirement for a strict GFD generally affected the social interactions of sufferers of CD, this effect is greater in women, as shown in this study and previous studies (Rose & Howard, 2014; Zarkadas et al., 2013).

Conclusions

This study shows that CD and its treatment reduce mental and social quality of life in women. Greater awareness of CD as a worldwide public health problem is needed (Catassi & Cobellis, 2007), and more support is needed to help patients with CD cope with the illness and its treatment. Finally, organizations and public institutions should carry out CD-related public awareness campaigns and help promote quality of life in sufferers of CD in general and in women in particular.

All of the participants discussed the importance of raising awareness in nurseries and schools and on television to promote greater public understanding of CD.

As treatment continues and GFDs are increasingly managed correctly, patients with CD gradually become less anxious and fearful about their disease and its impact on their lives. In addition, they concurrently generate valid coping strategies that correspond to an increase in well-being and a valid sense of release for effective daily operations.

This study is limited to a specific population of patients (women with CD). Thus, the findings are not generalizable to other populations because of the methods used. The researchers aimed to gain in-depth knowledge about the experiences of each participant. The findings are important to understand the disease process of women with CD and should be assessed by health science research professionals.

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*Address correspondence to: Julián RODRÍGUEZ-ALMAGRO, Department of Nursing, University of Alicante, Carretera San Vicente del Raspeig, S/N Alicante CP: 03690, Spain.
E-mail: jupij79@gmail.com

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